

Use of Patient Identifiers in the UWSOM Foundations Curriculum

A workgroup was initiated in 2017 to examine how we use identifiers in the UWSOM curriculum. Input was solicited from a very large pool of the UWSOM family. A few of the best practice guidelines are summarized below and refer to discussions in the foundations blocks in our short, written cases. The use of identifiers is challenging because they can promote existing biases against patient populations and individuals, but can also inform clinical reasoning based on health disparities and inform distribution of resources to where they will have the greatest impact. Best practices related to patient identifiers are evolving and we welcome your input. Because of the evolving nature of identifier use, you may encounter variations across clinical settings where you will train. It also would not be possible to generate such guidelines that incorporate all the richness of humanity and we acknowledge this reality and approach this task with humility. A session has been built into the first block to discuss identifiers after you will have had some experience with the curriculum.

Age

Identifier Workgroup Recommendation: *Age should be included in every case presentation (unless it is not known or you are talking about a group rather than an individual).*

Implementation Guideline:

Prevalence of many diseases will go up or down on the differential based on age. Patients may be offended by some terms and phrases that are less precise than the specific age. Age discrimination (known as ageism) has been defined as prejudice or discrimination because of a person's age and may actually place patients at risk. Therefore, we recommend:

- To use numerical ages in describing individuals, although in some cases a descriptive term such as neonate might be used, as is common practice in a given discipline.
- Ages might be given in days, months, or years depending on the stage of life of the patient.
- Attempt to avoid non-precise terms such as old, young, elderly in lieu use of actual age.

Sex and Gender

Identifier Workgroup Recommendation: Use the patient's personally-articulated gender identity term in the ID/CC.

- Additional information regarding gender identity/sex assigned at birth should be included in the social history.
- Information regarding history of or plans for gender affirming care should be included in the PMH or social history, as appropriate.

Defining Terms:

Chromosome Compliment (Genotype/Karyotype): The chromosomal constitution of an individual regarding their genotype and what sex chromosomes they possess (X, Y, etc). Generally female refers to individuals who are XX and male refers to individuals who are XY. There are additional variations in chromosomal constitution mentioned throughout the curriculum, for example Turner's syndrome (45X), Klinefelter syndrome (47 XXY) and others.

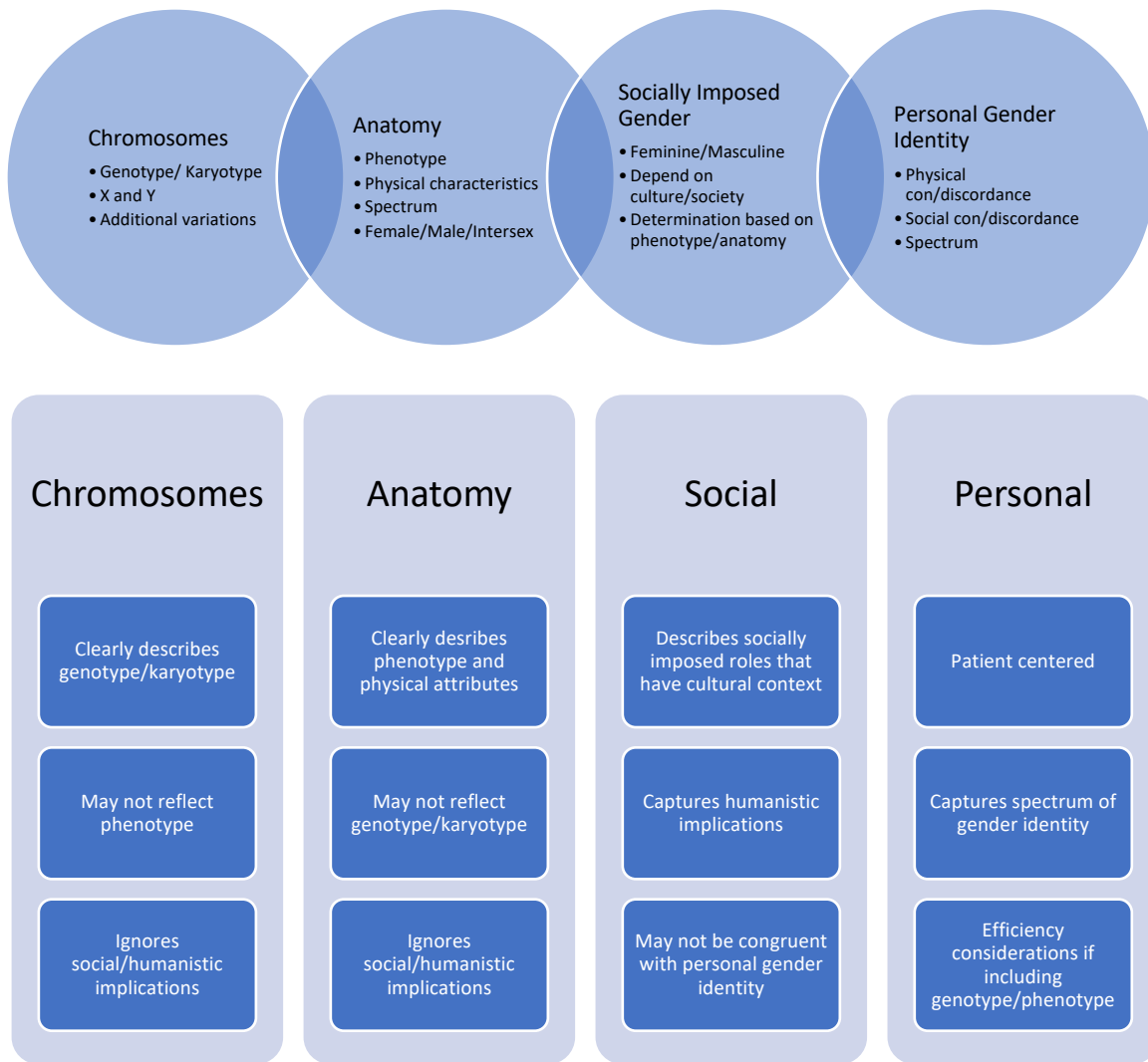
Anatomy (Phenotype): The anatomy or phenotype of an individual that describes physical characteristics of reproductive structures. Male phenotype or anatomy includes penis/testicles and female phenotype includes vagina/uterus/ovaries. This anatomy is often described as "sex assigned at birth". As with chromosomal constitution, there is diversity of anatomy with both external and internal structures. The phrase "diversity of sexual differentiation" or the term "intersex" captures this spectrum of physical characteristics. "Female" and "male" describe biological [sex](#)—in humans, non-human animals, and other organisms. "Females" and "males" should be used only when the subject matter in question is solely biological sex.

Socially Imposed Gender: The gender or social role of an individual which is first attributed or assigned to an individual, usually starting at birth, and based on anatomy or chromosomal compliment. The way "sex" and gender are assigned early in life will vary widely among cultures and with different socially derived norms for gender, and with qualities and behaviors considered "feminine" or "masculine." Terms associated with these socially imposed roles include "girl"/"boy"/"man"/"woman". Gender assignment can also determine how others perceive (accurately or inaccurately) a specific individual.

Personal Gender Identity: The gender identity that arises from the ways in which an individual person experiences their own body and social roles. Personal gender identity is not limited to binary options; there is a wide spectrum of possible gender identities. Personal gender identity can include social roles and behaviors far beyond the feminine/masculine dichotomy. Individuals can experience concordance and discordance with both their physical attributes and anatomy, as well as with their socially imposed gender. People who experience physical/social discordance can use the prefix "trans", while those who experience physical/social concordance may use the prefix "cis". Terms associated with personal gender identity can include

“transgender man”, “cisgender woman”, “transgender woman”, “cisgender man”, as well as “man”, “woman”, “male”, “female”, “non-binary”, and “genderqueer”, among many others. Personal gender identity can only be ascertained through direct discussion with a patient, and a physician should use the gender identity term personally articulated by that individual.

The diagram below presents an example of how these different terms and concepts can interact and some of the implications of using a particular approach:



Appropriate Examples (choose to be respectful, inclusive and to support clinical reasoning):
Chromosome

- ABC is a 23-year-old 46XX

Anatomy

- ABC is a 23-year-old female

Social

- ABC is a 23-year-old woman

Personal

- ABC is a 23-year-old cisgender female/woman (depending on patient's preference for gender term)

All

- ABC is a 23-year-old cis-gender woman assigned female at birth with 46XX chromosomes.

Implementation Guidelines: The identification/chief concern should include the patient's personally articulated gender term when the case is about a specific individual (when the individual could be asked their gender term). Information about chromosomes, sex assigned at birth, and identity should be added as needed to support respectful description, inclusion and clinical reasoning. Content describing populations should use terms that describe anatomical or phenotypic sex (female/male) and not gender terms (woman/man). Content describing populations is best limited to instances where there is clear evidence-based value to clinical reasoning, discussions of disparity, and epidemiology. Use the term "sex" when reporting biological factors (chromosomes/anatomy). Use "gender" when reporting gender identity or social or cultural factors.

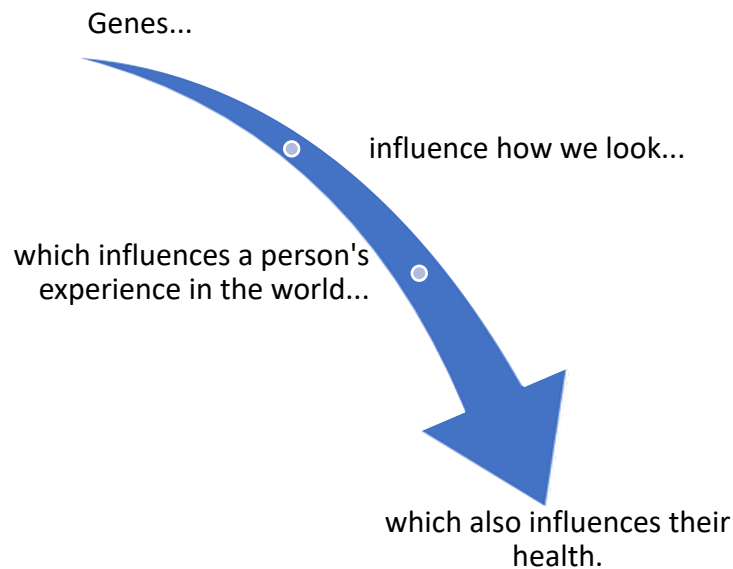
Resources:

1. An excellent overview of terms with very clear examples: [Stanford Gender Innovations in science, Health & Medicine](#) ("Terms" Tab).
2. Clayton, J. A. & Tannenbaum, C. Reporting Sex, Gender, or Both in Clinical Research? *JAMA* **316**, 1863–1864 (2016).

Race, nationality, ethnicity, ancestry

Identifier Workgroup Recommendation: *Do not use racial and ethnic identifiers in the ID/CC unless there is a clear, compelling, evidence-based reason for doing so.*

Human categories such as race are social constructs but do have an impact on health, as resources and stress are disproportionately distributed between the categories. It is also important to discuss and consider social constructs such as race to identify and address health disparities and their causes:



Health inequities are rooted in social and structural determinants and include everything from blood pressure to breast cancer to life span. In addition, there are many genetic disorders covered in the curriculum that are more or less common in different ancestry groups, for example cystic fibrosis, Tay Sachs, hemochromatosis or sickle cell anemia. Allele distributions vary across populations for several reasons that we will cover in the curriculum such as founder effects, environmental pressure, and population bottlenecks. This does not mean that one should ignore the distribution of disorders that are more common in a given group because of allele distribution, but rather recognize the social origin of categories such as race/ethnicity/nationality and be aware that these disorders are also found outside of populations in which they are more common.

There is not a gene for race, ethnicity, or nationality but the human-generated categories are sometimes used to imperfectly approximate different frequencies of disease associated alleles in a population. Ancestry is a more accurate measure of allele frequency; however, and knowing an individual's actual genotype will always be optimal. Because of the order of the curriculum we do cover many of the rare inherited disorders before the more common disparities rooted in social and structural determinants of health and want to acknowledge this here. And even though knowing an individual's actual genotype is optimal, the role that social and structural factors such as income inequality, racism, environmental causes have in perpetuating health inequities should not be downplayed.

Implementation Guidelines: The use of racial and ethnic categorization of patients and populations is flawed. There is often a lack of consensus about what race and ethnicity mean and how these should be operationalized within the medical field. There is evidence to suggest that highlighting a person's race and ethnicity as part of a clinical encounter can strengthen already established biases. Furthermore, there is no evidence that general inclusion of race and

ethnicity as part of case presentations carries any benefit. Similarly, there is a dearth of evidence for including these identifiers in evaluation and assessment materials (i.e. exams) throughout medical school. Therefore, describing patient population or heritage is best limited to instances where there is clear evidence-based value to clinical reasoning, discussions of disparity and epidemiology.

Resources:

1. Anderson, M. R., Moscou, S., Fulchon, C. & Neuspiel, D. R. The role of race in the clinical presentation. *Fam. Med.* **33**, 430–434 (2001).

Sexual Orientation and Practices

Identifier Workgroup Recommendation: *Use the patient’s personally-articulated term for their sexual orientation identity in the medical database. Information on sexual behaviors should be included in the ID/CC if it is relevant to the presenting concern. If unrelated to presenting concern, sexual behaviors should be included in the sexual history. Information on a patient’s personally-articulated sexual orientation identity should be listed in the social or sexual history.*

Implementation Guidelines: Do not include sexual orientation/behaviors in ID/CC. Be careful to not connect sexual orientation only when describing sexual behaviors or pathology. Behaviors and personally-articulated terms may or may not be congruent.

Resources:

1. Brooks, H. *et al.* Sexual orientation disclosure in health care: a systematic review. *Br. J. Gen. Pract.* **68**, e187–e196 (2018).

Ability

Identifier Workgroup Recommendation: *Information about ability or disability status should be included in the ID/CC when it pertains to medical decision making for the presenting concern. Otherwise the information should be captured in the problem list or past medical history. Patient-first or person-first language should be used.*

Implementation Guidelines: Be aware that a person’s or patient’s first language is not preferred by all members of that community. For example, some members of the Deaf and Hard of Hearing community prefer to identify using first language, i.e., a “Deaf person” vs. a “person with a hearing impairment”. The same can be true of other disabilities, i.e., “person with Down syndrome” vs. “Down syndrome patient”. Also avoid using possessive terms such as

“Down’s”, based on the historical practice of naming diseases and syndromes after their first describer. These will likely be found in the curriculum as this is the first year we are making this recommendation and we will correct them as they are identified. Similar considerations should be used for members of the Asperger-autism spectrum community.

Size

Identifier Workgroup Recommendation: *Do not refer to body size in the ID/CC unless pertinent (presenting concern is weight, size is pertinent to the patient care, deviation from expected weight trajectories).*

Implementation Guidelines: Body mass can be reported numerically as body mass index (BMI) which are correlated with terms such as “normal” or “obese”. Because terms such as “normal” and “morbidly obese” can be interpreted as judgmental, use the BMI numbers. Objective measures are preferred over diagnostic terms “obese” and “morbidly obese.” These diagnostic terms are seen as insulting by many patients and have been linked in some studies to implicit bias in providers, and consequently, health disparities for patients. If objective measures are not available, be aware that general descriptions of size can bias caregivers and offend patients. Use anatomically or medically descriptive rather than diagnostic terms.

- For example, if adipose tissue will limit access for a procedure or is contributing to a problem, describe the location and specific concern.
- Consider using an estimate of BMI range or weight.
- Avoid the heavily stigmatizing and nonpreferred term “morbid obesity”.

Resources:

1. Puhl, R., Peterson, J. L. & Luedicke, J. Motivating or stigmatizing? Public perceptions of weight-related language used by health providers. *Int. J. Obes.* **37**, 612–619 (2013).

Stigma

Identifier Workgroup Recommendation: *Patient-centered, nonjudgmental, strengths-based and collaborative language can help engage patients, improve outcomes and avoid stigma. Describe facts, strengths, goals, barriers. Understanding a patient’s possibly conflicting goals, priorities and resources can assist the team in collaboratively creating a treatment plan. This information may be recorded in the HPI, PMH, problem list, or social history as appropriate.*

Implementation Guidelines: Describe facts (“taking medications approximately 25% of the time,” “dressings not changed since last visit.”), strengths (“focusing on financial stability rather than on medical management over the past 3 months.”), goals (“Highest priority is finding

housing”). When possible describe barriers to reaching goals rather than failure to “adhere”. (“lack of insurance made filling all prescriptions difficult this month.”). Consider terms that are less value laden and more empowering such as “engagement”, “participation”, “involvement.” When a patient “declines” to participate in recommended care, describe the concerns or conflicting priorities that limit participation. (“patient declines surgery due to...”)

Other considerations

Other patient identifiers that may be helpful for clinical reasoning and patient care but could also promote bias are not included here. These might include but are not limited to class, citizenship, language, religion and political affiliation. As above these identifiers should be used with great care to promote optimal health care outcomes and avoid bias. This is a working document and we hope to expand on optimal practices.